Registry and Repository. CDEs consist of two parts: the Data Element Concept describes the form question and the Value Domain describes how the answer should be reported. Each CDE contains the metadata required for a form question. Questions requiring the same metadata are represented by a common CDE. In addition, the metadata in FN was moved from the question level to a cross-form data dictionary and linked to CDEs to further standardize the required data and its format.

Results: A review of the current baseline and follow-up forms indicates that harmonizing the data dictionary entries (DDC) with the CDEs has led to an approximately 25% reduction (583 DDCs and 437 CDEs) in the number of data points being defined multiple times. This has led to more consistent forms and data collection.

Conclusion: The CIBMTR's data collection forms include questions that are asked multiple times within and across forms. To facilitate data entry and analysis, form inconsistencies needed to be addressed. To help alleviate these issues, the data dictionary entry and metadata are tied to a CDE. In addition, a metadata review is now undertaken at each step in the form revision/development process to ensure questions are harmonized, terminology is used consistently, question formats are standardized, and the option values are semantically similar. Exceptions are only allowed when clinical differences and regulatory compliance dictate. The benefits of using well-defined metadata and data standards include unambiguous interpretation of data points, improved data exchange, facilitated data analysis, improved cross-form consistency, and the creation of a pool of data elements to be used for new form development.

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Transplant: The Ultimate Team Sport. A Potential Answer to Workforce Challenges in Hematopoietic Stem Cell Transplant

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A major challenge for transplanters, is how to meet the workforce capacity necessary to support the increase in transplants that are projected. This includes physicians, nurses, NP's and PA's, pharmacists, coordinators, social workers and many others who make up the transplant team. Despite the extensive hours often required, repeatedly when staff are asked what they enjoy most about transplant the word team comes up. In the summer of 2011 a clinically successful transplant program in Phoenix Arizona was closed due to a change in values at the parent institution. The transplant team wanted to continue to serve current and future transplant patients. After discussion with FACT it was recognized to maintain accreditation that all key personal or the “blood and guts” of the program must move together. In November 2011 the team moved to a new facility. Transplant SOP's and Quality manuals were completely rewritten. Follow up of existing patients began immediately, new patients were seen starting in January, an inpatient and outpatient unit was rebuilt and certified by the state in February and the first transplant was performed that month. At present the following have been performed. 250 Consults from 74 different providers 67 Apheresis Procedures 50 Transplants (29 Auto, 12 Sibling, 9 MUD) 4 Insurance company inspections 1 FACT Inspection During this time staff frequently worked overtime and yet their overall satisfaction scores went from 2.3 to 9.4. When asked to state the best thing about what they did the answer was virtually unanimous; the team approach. This approach increases satisfaction for the transplant team who often experience significant stress and pressure relative to the patients that they encounter. Using a team collaborative approach enhances feelings of accomplishment and improves satisfaction scores. Such an approach may be useful in dealing with the workforce challenges in the BMT field.

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Use of National Registry Demographic Data for Resource Planning

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Introduction: Australia's combination of a large land area (7.7 million square km) and relatively small population (22.7 million) contributes to unique resource planning issues for specialist services. The population density of Australia is 2.9 people per square km, compared with 32.7 in the USA, 256.3 in the United Kingdom and 337.4 in Japan. Despite high urbanisation in Australia, many patients need to travel long distances for treatment, particularly those receiving allogeneic transplants. In 2011, 498 allogeneic transplants were performed in Australia. With increasing post transplant survival and recognition of the long term follow-up needs of survivors, it is important to optimise the use of resources so that all patients have access to appropriate care.

Methods: Residential postcodes were available for 3,655 of the 4041 patients who received allogeneic transplants in Australia from 2002-2011 (90%). These postcodes were extracted from the ABMTRR database and converted via geocoding into latitude and longitude for display onto a map. This same method was used to obtain a location for the transplant centres. Distances from the residential postcodes to the transplant centres were calculated and analysed.

Results: The median distance travelled for allogeneic transplant patients in Australia was 25.7 km (range 0.1 km - 3,155 km). Thirty nine percent of patients travelled more than 50 km to their transplant centre, with 28% travelling more than 100 km and 6% travelling more than 500 km. On average, patients travelled longer distances to paediatric centres than adult centres.

Conclusions: Visualisation of referral patterns on maps and analysis of the distances between residential addresses and transplant centres are useful tools for developing follow-up protocols. It is anticipated that e-health services will become an important aspect of the long term care of transplant patients, and will be especially beneficial for patients in remote areas.